

Privacy Notice to Clinicians and Researchers

Effective Date: August 29th 2019

Welcome to BCM Registry! Your privacy is very important to us. This Privacy Notice applies to information that you provide to BCM Families Foundation (“**BCMFF**” “**we**,” or “**us**”) when you join the BCM Registry (the “**BCM Registry**” or the “**Registry**”) as a clinician or researcher, in accordance with the [Clinician Terms and Conditions](#) and the [Researcher Term and Conditions](#) that regulate your participation in the Registry.

For the purpose of this Privacy Notice, “**Researchers**” means researchers, scientists, universities, health and research institutions or associations, biotechnology and pharmaceutical companies and other third parties, who have agreed to comply with BCMFF’s policies and protocols with respect to the handling and future use of patients anonymized data (hereinafter, each of them, a “**Researcher**”).

For the purpose of this Privacy Notice, “**Clinicians**” means clinicians, doctors, physicians, or other medical professionals who treat patients with Blue Cone Monochromacy who have agreed to comply with BCMFF’s policies and protocols with respect to handling their patients’ data and patients anonymized data (hereinafter, each of them, a “**Clinician**”).

This Privacy Notice describes how we may collect, use, or share information about you and the ways in which we safeguard the information we collect, as well as how you may contact us regarding our privacy practices.

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Information We Collect

Information You Provide

We obtain information that you provide to us directly, for example, data you submit on the registration form. The information we collect includes personal information (such as your name and surname; the organization you belong to) and contact data (such as your mailing address, the e-mail address and the phone number).

You shall provide information that is accurate to the best of your knowledge, and you shall update your information as necessary in the future to maintain its accuracy.

Information Collected Automatically When You Use the Registry

In addition to information you submit to us, we may collect certain information using automated means such as cookies and web server logs, and other tracking technologies now and hereafter known or devised.

- A **cookie** is a piece of data that a website can send to your browser. The cookie may then be stored on your computer as an anonymous tag that identifies your computer when you visit a website. Many web browsers are set to accept cookies by default, but you may be able to set your browser to notify you before you receive a cookie, or to remove or reject cookies. The cookies used in the Registry are “technical cookies”, i.e. those cookies which allow users to navigate and use a website (e.g. to authenticate themselves). They are not used for further purposes and are installed directly by us. Your prior consent is not necessary to install these cookies, as without such cookies the Registry cannot work. Information obtained through such cookies are processed only to pursue our and your legitimate interest in ensuring the proper and correct operation of the Registry.
- Please be aware that if you disable the technical cookies or all cookies, you may not be able to use certain features of the Registry. Also, disabling cookies may invalidate opt outs that use cookies to recognize devices that have opted out.

The types of information we collect may include IP addresses, device identifiers, browser characteristics, operating system details, language preferences, referring URLs, length of visits, and pages viewed. We may combine this automatically-collected information with other information we obtain about you.

Follow the instructions given by the developer of your Internet browser to find out how to control, disable or erase some or all of the cookies:

Edge: <https://privacy.microsoft.com/en-us/windows-10-microsoft-edge-and-privacy>

Chrome: <https://support.google.com/chrome/answer/95647?hl=en>

Firefox: <https://support.mozilla.org/en-US/kb/enable-and-disable-cookies-website-preferences>

Safari: https://support.apple.com/kb/PH17191?viewlocale=en_US&locale=it_IT

Opera: <https://www.opera.com/help/tutorials/security/privacy/>

How We Use Information

We may use the information we collect about you for the following purposes:

1. to perform a contract which you are a party to (i.e. the [Clinician Terms and Conditions](#) and [Researcher Terms and Conditions](#) regulating your participation in the Registry) and pre-contractual measures adopted at your request ;
2. to pursue our legitimate interest in exercising or defending a right in judicial or out-of-court proceedings, also in the event of non-fulfilment of the Terms and Conditions.

We also may use the information we obtain about you in other ways for which we provide notice at the time of collection.

How We Share Information

We may permit our consultants and service providers, including IT services providers, acting as data processors, to access information we collect about you to carry out work on our behalf. These third-party consultants/service providers are prohibited from using such personal information for any purpose(s) other than to provide their services we have engaged them to perform.

We may share your information with third parties, acting as independent data controllers: (1) if we are required to do so by law, regulation, or legal process (such as in response to a court order or subpoena); (2) to fulfil requests by government agencies, such as law enforcement authorities; (3) when we believe disclosure is necessary for the establishment, exercise or defense of legal claims; (4) in the event of a joint venture, partnership, merger, or other collaboration with another organization, to the extent permitted by the law; or (5) in the context of a business negotiation or transaction relating to BCMFF or any affiliated entity (e.g., further to a merger, reorganization, liquidation, or any other business transaction), including negotiations of such transactions, to the extent permitted by the law.

If you are a Clinician, please know that Participants enrolled in the Registry will find your name within a list of “registered Clinicians” and might select you as their treating Clinician in charge of validating their diagnosis and medical data within the Registry. You should have seen and treated these patients before. However, they may select you even if they are not your patients, but they want to be seen by you. In this latter option,

you can choose whether or not to admit the patient and visit him in order to be able to validate his data within the Registry.

Information Security

We maintain appropriate safeguards to help protect personal information collected through the Registry from loss, theft, misuse, or other unauthorized access, disclosures, alteration, or destruction. Although we use reasonable efforts to safeguard information, transmission via the Internet is not completely secure and we cannot guarantee the security of your information collected through the Registry.

Links to Other Websites

The Registry may include links to other websites for your convenience and information. Websites that are operated by entities not affiliated with BCMFF may have their own privacy policies or notices, which we strongly suggest you review. BCMFF is not responsible for the content or privacy practices of any linked websites that we do not control.

Retention period

Your personal data is retained subject to our retention policies and procedures unless and until you request the removal or deletion of such data or the Terms and Conditions regulating your participation in the Registry terminates for any reason whatsoever.

Your Rights/How to Update, Change, or Delete

Your Information

You have the right to exercise at any time, free of charge and without formalities the following rights: the right to request access to personal data (or the right to obtain from us the confirmation that data concerning you are being processed and, if so, to obtain the access to personal data, obtaining a copy of them) and correction (i.e. the right to obtain the correction of inaccurate data concerning you or the integration of incomplete data) or the deletion of the same (meaning the right to obtain the erasure of data concerning you, in the cases permitted by the applicable privacy law) or the limitation of the processing related to you (meaning the right to obtain, in the cases provided for by the applicable data protection law, the marking of data retained with the aim of limiting their processing in the future), in addition to the right to data portability (i.e. the right, in the cases permitted by the applicable privacy law, to receive from us, in a structured, commonly used and machine readable format the data concerning you, and to transmit it to another data controller without impediments). You also have the right to withdraw your consent at any time. The withdrawal of consent does not affect the lawfulness of the treatment based on consent before revocation. You also have the right

to object at any time, on grounds relating to your particular situation, to the processing of your personal data, based on legitimate interest, including profiling. We remind you that you always have the possibility to lodge a complaint with the competent Data Protection Authority.

You can exercise the above-mentioned rights by contacting BCMFF by mail or by email as indicated in paragraph “How to Contact Us” below.

You can also directly and autonomously update, correct, or delete your information collected through the Registry by signing in and following instructions.

International Transfers

We operate the Registry in the U.S. and the information we collect is governed by U.S. law. If you are accessing the Registry from outside of the U.S., please be aware that information collected through the Registry may be transferred to, processed, stored, and used in the U.S. Data protection laws in the U.S. may be different from those of your country of residence. Your use of the Registry constitutes your consent to the transfer to and from, processing, usage, sharing, and storage of your information, including participant data, in the U.S. as set forth in this Privacy Notice.

DPO and Representative in Europe

We inform you that we have appointed a Data Protection Officer, which you can contact as follows for any question or information relating to your privacy and the protection of your personal data: avv. Italo de Feo (by mail to “CMS Adonnino Ascoli & Cavasola Scamoni, Via Agostino Depretis, 86, 00184, Rome, Italy, to the attention of avv. Italo de Feo” or by e-mail to dpo@bcmfamilies.org).

We also inform you that we have appointed a representative of BCMFF in Europe (Italy), that you can contact as follows: Dr. Renata Sarno, by mail to “Renata Sarno, Viale Tito Livio 76, 00136, Rome, Italy” or by email to Renata.Sarno@BCMFamilies.org.

U.S. Visitors

Your web browser may have settings that allow you to transmit a “Do Not Track” signal when you visit various websites or use online services. Like many websites, the Registry is not designed to respond to “Do Not Track” signals received from browsers. To learn more about “Do Not Track” signals, you may wish to visit <http://www.allaboutdnt.com/>.

We do not share personal information as defined by California Civil Code Section 1798.83 (“Shine the Light law”) with third parties for their direct marketing purposes.

Changes to this Privacy Notice

We may change this Privacy Notice from time to time. If we make changes, we will notify you by revising the date at the top of this Privacy Notice. We encourage you to review this Privacy Notice whenever you visit the Registry to stay informed about our information practices.

How to Contact Us

If you have questions regarding this Privacy Notice you may email us at:

Registry.Manager@BCMfamilies.org

or write to us at:

BCM Families Foundation
Attn: Privacy Inquiry
P.O. Box 7711
Jupiter, FL 33468-7711 USA